

ORAL PRESENTATION

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The European research area network – E-Rare

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Rare diseases represent an important public-health issue, affecting 26-30 million persons across Europe, and a major challenge for research. The fragmentation of resources and knowledge for the 6000-8000 rare diseases and the lack of efficient treatments for many of them necessitate a coordinated European approach to unravel the underlying molecular defects and pathophysiological mechanisms. The low number of affected patients requires transnational collaboration with multidisciplinary approaches to map prevalences, build patient registries, identify biomarkers, develop new diagnostics and finally perform clinical studies for the development of treatments. To this end, 8 main European research funding organisations have gathered into the PF6-funded EC ERA-Net on rare diseases (E-Rare) (2006-2010) and developed a number of joint activities regarding systematic exchange of information and best practises, definition of strategic priorities, and, most importantly, joint funding activities through the launch and completion of two fully fledged joint transnational calls for research projects on rare diseases (2007 and 2009). This exemplary joint funding activity has attested the need of, and the acknowledgment from, the research community for transnational funding of collaborative, multidisciplinary and ambitious projects on rare diseases. It has leveraged funding for rare disease research in countries that do not have specific programmes for rare diseases and thus enabled the participation of researchers in these countries to transnational projects. A new E-Rare project (E-Rare-2) (2010-2014) aims at deepening and extending the cooperation among the E-Rare-1 and four new partner countries by systematic exchange of information, yearly launched joint calls, thorough assessment of the funding mechanisms and results of the funded research projects and, finally, strategic activities aiming at a sustainable development and

extension of the network. Special attention will be given to the outreach and knowledge exchange with new Member States, countries outside of the European Union and key stakeholders/initiatives important for rare diseases. E-Rare-2 activities will thus further contribute to reducing fragmentation of research and resources through the enhanced coordination and transnational funding of excellent research on rare diseases, thereby shaping the European Research Area for rare diseases.

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